

NATIONAL INSTITUTE ON AGING

AIDS AND AGING RESEARCH

**CURRENT RESEARCH ACTIVITIES AND PRIORITIES
IN THE BEHAVIORAL AND SOCIAL SCIENCES**

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BACKGROUND AND RATIONALE

The behavioral and social implications of AIDS for the middle-aged and older population have been largely ignored. This is despite the fact that people age fifty and older have constituted approximately ten per cent of the reported AIDS caseload since the beginning of the epidemic. Findings showing that some middle-aged and older people do indeed engage in risky practices suggest that a dedicated effort is needed to identify older people's AIDS-related risk behaviors and to develop preventive strategies for modifying any risky behaviors. As successful regimens for postponing AIDS conversion and mortality proliferate, more people can be expected to age with HIV/AIDS. Furthermore, middle-aged and older people are increasingly being called on to care for younger family members with the AIDS virus or to share health care resources with the growing number of AIDS victims. Thus, AIDS is a public health problem affecting Americans of all ages. As such, research on AIDS in the middle and later years is increasingly important and can no longer be ignored.

NIA has a special research emphasis on the social and behavioral aspects of middle aged and older people in the AIDS epidemic. This includes attention to AIDS-related health behaviors of middle aged and older persons, the influence of the disease in younger persons on their older family members, and the impact of AIDS on the health care system and other social institutions used by older people. Trials of social and behavioral interventions for modifying older people's AIDS-related attitudes and behaviors are encouraged as are interventions for helping older people in their caregiver roles. The support of behavioral research on AIDS is seen as having an interactive effect on behavioral research on aging: AIDS-related research will draw upon basic behavioral research that has been conducted on other diseases and age groups, while in turn AIDS behavioral research will inform general behavioral research on aging.

SUMMARY OF PAST PROGRAMMATIC EFFORTS

NIA-lead activities

In 1987, NIA instituted a small workgroup to discuss behavioral and social aspects of AIDS and aging issues. These activities resulted in a now classic volume: AIDS in an Aging Society: What We Need to Know (edited by Matilda Riley, Marcia Ory, and Diane Zablotsky) which highlighted what was then known about AIDS and older people in terms of risk factors and prevention, care, and social consequences. Future research, prevention, care and public policy issues were also discussed.

In 1995, The NIA established a Trans-NIA Working Group on AIDS and Aging (Chairperson: M. Ory). Several goals have been identified by this Working Group, including to: 1) exchange information on what different NIA units are doing regarding AIDS and aging issues; 2) set up a mechanism to respond in a timely fashion to

requests; 3) identify key research interests across different programmatic areas; and 4) make NIA's research interests more visible.

In 1997, the NIA, in conjunction with NIMH, NINR, and OAR/NIH has held a Conference titled AIDS and Aging: Identifying a Prevention and Care Research Agenda. The purpose of this conference was to commission a set of papers and assemble a panel of experts to review what is known, identify research gaps, and recommend future directions for research. Topics covered include: 1) the social epidemiology of older people at risk; 2) the presentation of AIDS symptoms in older adults, and the impact of age on the trajectory of the disease; 3) living with HIV/AIDS and the consequences of HIV/AIDS on informal and formal care systems; 4) social and behavioral interventions to change older people's AIDS-related attitudes and behaviors and to help older people enhance their caregiving capacities (e.g., for adult children or grandchildren with AIDS); 5) methodologies for improving prevention research in middle-aged and older populations; and 6) sub-cultural and cross-national perspectives in HIV/AIDS prevention research and care. This Conference was seen as a ten year update to the original 1987 Conference on AIDS in an Aging Society. Papers from the Conference will appear as a special supplement to *Research on Aging* in November, 1998.

In addition to the Conference, two recent program development activities have been implemented. First, AIDS and Aging research was listed as one of the limited eligible topics for NIA's small grants program. The purpose of the small grant announcement was to give priority to underdeveloped areas that can be made more competitive by providing support to conduct pilot or exploratory studies. Topics solicited, for FY98, include behavioral, social, clinical, neuroscientific, and/or biological research on older people infected by and affected by HIV/AIDS.

At the same time for those researchers who already have pilot data, NIA has spearheaded a new ongoing program announcement on AIDS and Aging: A Behavioral Sciences Prevention Research co-sponsored with NIMH and NINR. Of particular interest is the examination of the impact of sociodemographic factors such as age, race/ethnicity, and gender on the development of AIDS-related attitudes and behaviors as well as responsiveness to preventive interventions for changing behaviors or reducing caregiver burdens. Specific objectives are to: 1) identify social and behavioral factors associated with HIV transmission and disease progression in later life; 2) examine behavioral and social consequences of HIV infection/AIDS across the life course; 3) develop and evaluate age appropriate behavioral and social interventions for a) preventing AIDS in middle-aged and older adults and/or b) ameliorating problems associated with older adults' caregiver responsibilities and burdens; 4) explore health care issues surrounding AIDS care; and 5) strengthen existing research and evaluation methods.

Collaborative Efforts

The NIA is continuing to marshal limited resources by collaborating with other agencies in identifying and funding research projects relevant to AIDS and aging issues, including the following:

Through an interagency agreement, NIA has provided support to the National Academy of Sciences/National Research Council's Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences.

NIA has participated in a NIH-USAID international behavioral research program. In 1990, an RFA on Behavioral Research in Support of AIDS Prevention was released, with two goals to accomplish: a) to support basic research that will provide information concerning high risk behaviors and behavioral changes relating to the transmission of HIV infection throughout the life course, and b) to strengthen capabilities in developing countries to design and carry out behavioral research and prevention programs to reduce the transmission of HIV infection.

NIA has co-sponsored several program announcements, including a trans NIH-ADAMHA announcement on Behavioral Change and Prevention Strategies to Reduce HIV Transmissions in 1988. More recently, NIA co-sponsored another trans-NIH program announcement on Behavioral Factors in the Transmission of Sexually Transmitted Diseases. Focusing on middle aged and older populations, NIA calls attention to the underlying need for additional research on the patterns and modifiability of high risk sexual behaviors in middle-aged and older persons.

NIA is collaborating with NIMH on two AIDS-related research solicitations, along with NIMH, NIDA, and NIAAA, the NIA co-sponsored a RFA on Family Interventions and HIV/AIDS. Three major research areas have been identified: 1) the education of family members about the potential risk to older persons, which is often minimized by stereotypic assumptions that older people are no longer engaged in sexual activities and behaviors; 2) teaching middle-aged and older family members to be agents of behavioral change in their interactions with younger family members; and 3) supporting the role of the older generation family members who have become primary caregivers due to AIDS-related incapacitation or death. Seven sites were funded to examine a wide range of interventions targeted at different populations (e.g., women, children, teenagers, older adults). The grant from Memorial Sloan-Kettering Cancer Center is being co-funded by NIA as it takes an intergenerational approach to strengthening family problem solving to cope with AIDS.

NIA's aging interests are also listed on an ongoing NIMH program announcement on Brief Interventions to Prevent the Spread of HIV. The purpose of this announcement is to solicit research on methods and techniques for motivating people to assess their risk for HIV and to seek additional behavioral change help.

Other national aging groups are also recognizing older people as a neglected segment of the AIDS epidemic. In recognition of the importance of AIDS for an aging society, the AARP Women's Initiative held a special seminar to discuss how HIV/AIDS affects mid-life and older women in 1993. Discussion centered on behavioral risk factors, physiological risk factors, diagnosis and treatment, and mid-life and older women as caregivers. This seminar has resulted in a published volume, Mid-life and Older Women and HIV/AIDS which identifies recommendations relevant to research, prevention, care and treatment, law and ethics, and policy development needs. In recent years there have also been symposia on AIDS and Aging at annual meetings of the Gerontological Society of America, and there is now an Interest Group devoted to exchange of information on AIDS and Aging issues.

NIA now has representation on the NIH Office of AIDS Research (OAR) Coordinating Committee for Behavioral, Social Science and Prevention Research. This enables NIA to share knowledge about scientific findings and opportunities in the social and behavioral sciences.

NIA FUNDED RESEARCH ACTIVITIES: SELECTIVE HIGHLIGHTS OF BEHAVIORAL AND SOCIAL RESEARCH

National Surveys of AIDS-Related Behaviors

The "National AIDS Behavioral Research Survey" supported by the National Institute on Mental Health (NIMH) is the only national survey of sexual behaviors, HIV test-seeking, HIV related beliefs, and intravenous drug that includes older persons. It consists of approximately 12,000 white, black and Hispanic respondents 18-75. People 50-75 were oversampled because so little was known about older people's AIDS-related risk behavior.

In 1990 NIA engaged in an IAA with NIMH (Y2-AG-0147) to provide additional retesting of older respondents. In 1992, the University of California at San Francisco was awarded a continuation grant (PI: J. Catania, R01 MH/AG 48642) to follow up the original cohort and to examine changes over time. The NIA has recently entered into a second three year interagency agreement (FY 92-95) with NIMH to ensure that budget cuts do not necessitate dropping the oldest cohorts who will be most expensive to interview and that specific analyses are conducted on the older population.

The first preliminary analyses were presented at a 1991 GSA symposium on the Place of the Older Person in the HIV epidemic. More recent published analyses reveal that HIV prevention programs are not directed at or reaching middle aged and older heterosexuals with multiple sex partners who are at risk for HIV. (c.f., "Prevalence of AIDS-related Risk Factors and Condom Use in the United States" Science 258: 1101-1106, 1992; "AIDS RISK Behaviors among Late Middle-Aged and Elderly Americans" Archives of Internal Medicine 154: 57-63, 1994; "AIDS Related Risk Behaviors and

Safer Sex Practices of Women in Mid-life and Older Women: 1990-1992", under review).

Family of AIDS Behavioral Surveys

In FY95, NIA cofunded the "Family of AIDS Behavioral Surveys" (PI: J. Catania, R01 MH/AG 51523) to support primary data collection on older persons (e.g., 50 years and older) regarding AIDS risks and caregiving issues. NIA's contribution helps assure that issues relevant to middle aged and older persons are addressed in this study of adults eighteen years of age and older (. As successful regimens for postponing AIDS conversion and mortality proliferate, more people can be expected to age with HIV/AIDS. n= 10,000 with oversampling of African Americans and Hispanics). Data collection for this national survey was completed in 1996, and analysis is currently underway. In comparison with earlier surveys, the Family of AIDS Behavioral Surveys will permit national-level examination of changes in prevalence of HIV risk factors, HIV/AIDS related beliefs, and sexual negotiation skills over time. This survey research will provide a broad perspective on human sexuality across the adult life-span, including the most in-depth assessment on the sexual behavior and relevant correlates of these behaviors and experiences among older adults in the United States. There are currently 2653 respondents 50 and older, with 781 respondents being 70 and older. The availability of 200 respondents 80 and older will provide a rare look into AIDS-related attitudes and behaviors in the very old. In addition, information was gathered on perceived risk relevant both to HIV and other sexually transmitted diseases. The emphasis is on Hispanic family variables, HIV testing, and attitudes and beliefs about the recently approved home HIV test kit.

Sexual Behaviors in Middle Aged Women

An administrative supplement has been awarded to N. Avis for her grant "Is Age-Related Decline in Sexual Activity Inevitable?" (R01 AG11379) to examine patterns of sexual activity and HIV/AIDS risk factors among a non-patient based sample of middle-aged women. Drawing on a long- term study of women as they approached and experienced the menopause, this supplement will contribute to our limited understanding of sexual behaviors by obtaining standardized information from a large representative of community dwelling women. Adding questions to the final interview on knowledge about AIDS, personal risk of getting AIDS, and discussions with others about AIDS, the investigators found that women aged 59-68 in their study were generally knowledgeable about AIDS, nearly a quarter knew at least one person with AIDS, and most had talked with their children about AIDS. These women perceived themselves to be at low risk for AIDS, but they may underestimate their risks due to unknown practices of their partners.

Risk Behaviors of Older Drug Users

A neglected area of research is studying the risk behaviors of older persons who are illicit, injecting drug users. The pilot research by J. Levy ("HIV-Risk Among Older Drug-Injectors," RO3 AG16041-01) identifies and examines age-related factors (e.g., biological aging, social networks) and mediating factors (e.g., gender, perception of risk) that influence HIV risk among illicit, injecting drug users (IDUs) who are 50 years of age or older and not in treatment. The participants will be sampled from a pool of IDUs enrolled in a community-based HIV counseling, testing, and partner notification project. The researchers will conduct a focus group session as well as in-depth individual interviews to collect information that will be used to develop an age-appropriate, HIV-prevention model for older injectors that can be implemented and tested at multiple sites in future efforts.

Improving Behavioral Measurement

NIA is co-funding a joint NIA-NICHD project entitled "Survey Measurement of Sensitive Behaviors Using Audio-CASI" (R01 HD/AG 31067) by C. Turner. This project is geared toward developing improved methods for collecting health survey data, including information on AIDS-related risk behaviors in adults. The research has focused on using a new technology called audio computer-assisted self interview (Audio-CASI) to improve representation of linguistic minorities in national health surveys. Findings can also be applied toward the collection of sensitive information in middle and older aged-populations.

HIV Infection and Cognitive Functioning

K. Goodkin and colleagues previously have found that cognitive-motor impairment is associated with an increased risk of mortality in HIV-positive individuals, even for those who are not experiencing any additional symptoms of AIDS. Therefore, these researchers ("AIDS and Aging: Behavioral Sciences Prevention Research", RO1 MH58532-01) are studying the combined effects of aging and HIV on cognitive ability to determine if the combined effects are merely additive or if they are multiplicative. The research sample will consist of three groups: AIDS diagnosed individuals, HIV+ individuals (have not contracted AIDS yet), and HIV- individuals. Their performance on a cognitive battery will be beneficial in distinguishing between dementia brought about by HIV infection and dementia brought about by other aging processes.

F. Wilkie ("The Impact of HIV Infection and Aging on Task Performance", RO3 AG15232-01) intends to assess the impact of HIV infection on the cognitive functioning of older adults and the implications of HIV infection and aging on the performance of real world cognitive tasks. The research sample will consist of three groups: HIV-1 negative, HIV-1 positive (early symptomatic stage), and HIV-1 positive (late symptomatic stage). Over a span of two days, participants will complete a battery of cognitive tests as well be trained to perform a real world computer task. Data will

include measures of cognitive ability, task performance (speed and accuracy), and measures of fatigue and stress. The results of this study should offer insight as to the impact of cognitive impairments due to HIV infection and aging on the quality of life of older adults.

Living with AIDS

The psychosocial adaptation of middle aged and elderly individuals living with HIV is the focus of a newly funded study by K. Siegel (R01 AG11379). The research focus will be on determining similarities and differences in adaptive tasks posed by the illness, coping responses, and other adaptational outcomes among infected adults 50 years and older (recruited from the greater New York City metropolitan area) from three race/ethnic groups: native-born (non-Hispanic), white, native-born African American and Puerto Ricans. The aim of this project is to understand how HIV-infected older adults adapt to their condition and how this may vary by race/ethnicity, gender, and by disease stage. A qualitative research design is proposed to explore these understudied areas, with the goal of guiding the design of a subsequent survey study. A supplement to this project will permit investigators to examine older people's use of and compliance to new combination therapeutic drug regimens.

The focus of the study by T. Heckman ("Improving Coping Skills in Older Persons with HIV/AIDS, R03 AG16034-01) is to characterize the daily stressors, coping strategies, availability of coping assistance resources, and quality of life among HIV-infected persons 50 years of age and older. The first step will be to conduct a focus group to assess critical psychosocial issues and events that may tax coping abilities and reduce quality of life. The second step consists of administering a self-report survey containing quantitative measures of relevant variables such as ways of coping, quality of life, distress, and social support. The project will conclude with a pilot test of a small-scale, coping effectiveness intervention for adults 50 years of age or older living with HIV/AIDS. The results of this project will guide the conceptualization and protocol formation of a large-scale intervention proposal to be submitted after the completion of this pilot work.

The study by A. Justice ("Mediators of Age-Associated Outcomes in HIV infection", K08 AG00826-01) has three specific aims: 1) To identify mediators of age-associated survival in people with HIV; 2) To identify mediators of age-associated quality of life in people with HIV; 3) To identify mutable mediators (e.g., social and personal risks and resources and timely access to appropriate medical care) of age-associated disease burden in people with HIV. The research plan addresses these aims in three samples: 1) A composite of 8 HIV drug trials; 2) computerized data available on a contemporary cohort of patients from 4 sites of care; 3) prospectively collected data employing quantitative and qualitative methods to more thoroughly explore mutable mediators of age-associated outcomes. The findings of this research should contribute to improving the outcomes for middle-aged and older people with HIV.

Formal and Informal Care For Persons with AIDS

The anthropological research conducted by J. Kayser-Jones ("An Ethnography of Dying in a Long-Term Care Facility, RO1 AG15806-01) examines the social, cultural, environmental, and clinical factors that influence care delivered to residents of nursing homes who are expected to die within 12 months. It will examine resident characteristics and processes of managing the physical, psychosocial, and spiritual care of dying residents. Two nursing homes, both with special AIDS units are included in the study. This research will investigate whether the diagnosis of AIDS influences staff communication with patients and if the quality of care received is affected by that diagnosis and will further enrich our knowledge of the role of stigma in the death and dying process.

A four year study by J. Mullan ("Stress and Coping Among AIDS Caregivers", R01 AG 12910) assesses how family and non-family caregivers respond to caregiving tasks and adapt to other daily life stresses (e.g., bereavement). Applying a general stress and coping framework to the study of AIDS, this research will add valuable insight into the similarities and differences in coping with AIDS. Continuing previous research efforts, this study will encompass diverse age and family/generational relations between caregivers and people with AIDS by examining two populations: 1) one sample of traditionally defined family relatives (e.g., mothers, siblings, spouses); and 2) a second sample of caregivers unrelated by conventional family ties (e.g., partners/lovers and friends of people with AIDS). A major focus of this research will be on caregiving stresses and the intensity and duration of grief and distress associated with death and dying, and how these processes are modified by caregiving characteristics and the presence or absence of personal and social resources.

A supplement was awarded to S. Crystal ("Family Support Dynamics in HIV Illness", R01 MH/AG 51010) to support analysis of social support and health care utilization by older persons with symptomatic HIV disease. New modeling techniques are providing more accurate information on functional impairment trajectories for persons with HIV disease. More precise estimates of changes in functional status are important in planning for a response system for both informal and formal care.

Family Interventions for Coping with AIDS

As part of the 1995 NIMH/NIA RFA on Family Interventions and HIV/AIDS, NIA is co-funding one grant with NIMH. This five-year study by B. Rapkin (R01 MH55770) is based on a widely used social problem-solving model that enhances general skills for coping. This project examines how families affected by AIDS cope with the many sources of stress, including barriers to support and services. The proposed intervention is intended to help families develop flexible coping skills to gain the supports and services they need. Many multigenerational issues will be addressed, including disclosure, permanency planning, intergenerational differences in acculturation/ transculturation, the effects of illness on performance of familial roles

such as elder care, and intrafamilial differences in the ability and willingness to draw on formal and informal supports.

Educational and Dissemination Efforts

To combat the poor knowledge that middle-aged and older people have about AIDS, a Small Business Innovative Research project (PI: R. Strombeck, "AIDS and AGING: What People over 50 Need to Know", R44 AG 13248) is designed to develop and test a discussion-based, peer-led HIV/AIDS education model that will be made commercially available to organizations and agencies that provide services to adults 50 and older. This project should produce a low-cost product that can be used by community groups and organizations to educate older adults about HIV/AIDS.

The NIA also has incorporated AIDS information as part of its series of popular Age Pages on health topics for older people. "HIV, AIDS, and Older Adults" is a pamphlet, updated periodically, that reminds older people of their potential risks, briefly explains the disease and treatments, and lists several resources for additional information and assistance. (The AIDS as well as other Age Pages are available from the NIA Information Center, P.O. Box 8057, Gaithersburg, MD 20898-8057, or, toll free, 1-800-222-2225.)

Cost and Utilization of Care

The HIV Cost and Services Utilization Study (HCSUS), conducted under a cooperative agreement between the Agency for Health Care Policy Research and RAND, is a large effort to characterize the care of HIV disease in the contiguous United States. Preliminary findings from the predecessor study, the AIDS Cost and Service Utilization Study (ACSUS), show that older patients with HIV infection are roughly similar to younger patients with respect to route to exposure, distribution of illness state, and utilization of services. The goals of the current project are to study the cost and utilization of care, quality of life, clinical status, coping and social support, caregivers, medical providers, knowledge, and mental health and drug abuse issues. The core study will examine 3300 patients and their providers selected from 58 major and 120 minor practice sites in 28 urban locales, plus 20 providers in 5 rural locales. NIA is providing support over a four-year period to engage in activities such as: inclusion of age-specific comparisons of basic variables in high profile reports; topics specific to the older HIV-infected patient, such as access to and source of care, unmet needs, insurance status, disease severity, and quality of care; and examination of the burden of caregiving on non-infected older persons.

Special Care Units -- AIDS Supplement

This AIDS Supplement (J. Leon U01-AG10317) is a new component of the existing National Census of Specialty Units in Nursing Homes -- Trends in Special Care Census (NESCOU-TSC). The TSC census offers a cost efficient opportunity to learn how the nation's nursing homes are responding to the AIDS crisis, and will lay the groundwork for conducting more refined studies of AIDS specialty units by providing a national sampling frame appropriate for stratifying the identified AIDS units along various dimensions. Detailed telephone surveys with administrators in charge of specialized AIDS units and programs will identify characteristics of residents, specialized programmatic features, staffing characteristics, reimbursement, and referral networks.

Intervention Efforts in Developing Countries

As part of the NIH-USAID international behavioral research program, NIA has provided support for a project which examines the use of peer group supports and peer-led education to reduce the transmission of AIDS in Botswana (PI: K. Norr: "Gender and Peer Education for AIDS Prevention in Botswana", R01 AG 10499). After conducting interviews to assess women's AIDS-related attitudes and behaviors, the investigators will design educational and aids-prevention behavioral strategies that can be incorporated into existing women's groups in the community. This study is in the final phase, with attention focused on the most effective ways to organize peer groups and to identify peer group leaders. Pilot findings show the development of more positive attitudes toward condom use among the women in the program, and the promotion of safer sex among family, friends, and community members. Supplemental funds were awarded for limited pilot work to test the effectiveness of different ways to use peer-based intervention models relevant to middle aged and older adults. Two conferences have been held to disseminate the findings from this project.

FUTURE PLANS AND DIRECTIONS

Research Priorities

AIDS-SPECIFIC RESEARCH

NIA has identified several priority research areas, consistent with recommendations from OAR/NIH's Research and Budget Plans. The primary goals of NIA sponsored research are to: 1) understand social and behavioral factors associated with HIV transmission and disease progression; 2) develop and evaluate behavioral and social interventions appropriate for middle-aged and older people; 3) examine behavioral and social consequences of HIV infection/AIDS across the life course; and 4) identify needed improvements in research and evaluation methodologies. The NIA has identified the following research objectives and strategies for increasing knowledge on social and behavioral aspects of AIDS in the middle and later years.

Understanding HIV Transmission. Within a life-course perspective, the focus in this area is to determine the spectrum and frequency of behaviors and practices associated with risk of HIV transmission, within the general population as well as among various regional and demographic sub-populations. Once an accurate understanding of the links between behavioral practices in middle and later life and HIV transmission are formulated, appropriate intervention strategies can be developed to prevent and control the epidemic. Topics to explore include:

The nature and extent of HIV risk behaviors in the middle-aged and older population;

Models of behavior change that integrate biological, psychological, and social perspectives to explain and predict the acquisition and maintenance of HIV-related behaviors among middle-aged and older people;

Social and cultural factors of older people -- such as socioeconomic status, ethnicity; gender; marital status, social networks -- that influence HIV-related behavior and affect access and delivery of care;

Changes in HIV risk within individuals and dyads over time as a function of transitions and life-course events, such as changing family relationships, separation/divorce, or aging.

Behavioral and Social Interventions. In the past 15 years research has improved our understanding of HIV/AIDS prevention through behavior change interventions. Intervention models supported by the NIH have led to marked changes in sex and drug-using behaviors linked to HIV transmission. However, an expanded research base is needed to understand effective behavioral and social interventions for the older population, typically ignored in AIDS prevention activities. Topics to explore include:

The modifiability of behaviors associated with HIV transmission in middle-aged and older adults;

Intervention research to improve knowledge about HIV/AIDS and to encourage appropriate attitudes and behaviors to prevent HIV transmission in adulthood and old age;

Older people's attitudes toward as well as adherence, recruitment and retention in clinical trials of new drug treatments and vaccines;

The use of middle-aged and older populations as agents for modifying high-risk behaviors in younger populations.

Behavioral and Social Consequences of HIV infection/AIDS Across the Life Course. Another important goal of social and behavioral research is to reduce the negative impact of AIDS on HIV-infected individuals, their families, and the

communities and social groups in which they live. In addition, the impact of HIV/AIDS on the health care system needs to be examined more closely, particularly as individuals with HIV are living longer with the condition. Topics to explore include:

The psychosocial needs of HIV-infected individuals and their families, with particular attention to older persons, in coping with the chronic and fatal nature of HIV disease;

The special intergenerational impact of HIV infection and AIDS on middle-aged or older people called upon to care for younger family members or friends with AIDS;

The impact of the AIDS epidemic on older people's access to and use of long-term care;

The implications of the AIDS epidemic for developing new health care structures of relevance to older people (e.g., the mobilization of informal health networks).

Research and Evaluation Methodologies. This area focuses on the need for development and evaluation of methodologies for basic and applied research on HIV-related behaviors and associated outcomes for middle-aged and older people. Methodological advances are needed to further our understanding of HIV-related behaviors and behavior change, the linkages between behaviors, transmission, and disease progression, and the evaluation of interventions. Topics to explore include:

Innovations in quantitative and qualitative methodologies to enhance HIV-related behavioral and social science research in the older population;

The inclusion of older people in surveys to determine the prevalence of high-risk sexual activity and other AIDS-related behaviors in the United States;

Methods for obtaining accurate self-report measures of HIV-related behaviors and behavior change, and validation of self-report measures; Issues involved in obtaining sensitive information from older persons, and from persons with diverse backgrounds, languages, and cultures.

Improvements in methodologies for forecasting and modeling the AIDS caseload, health care needs, and health care utilization given different treatment and survival scenarios.

INVESTMENT AREAS

Forecasting and Modeling of Health Related Events. While there has been much improvement in AIDS epidemiology over the past decade, there are still methodological limitations in estimating the AIDS caseload, predicting health care needs, and forecasting health care utilization of persons infected with the HIV virus. We recommend an investment in basic methodological approaches to forecasting and

modeling health related events. The NIA has made progress on aging related events (e.g., morbidity, active life expectancy, disability) and proposes to investigate the applicability of existing methodological approaches to the study of the AIDS epidemic. If funds were available, we could envision releasing a solicitation for small scale methodological projects.

Measuring Cognitive Status. The impact of AIDS on cognitive functioning is an important issue deserving future attention. To improve research in this area, we propose support for research on basic cognitive processes, and in particular on strategies for developing standardized cognitive assessments in persons with AIDS. There is a foundation of previous work both on normal aging and dementia that can be applied to this area of study.

Understanding Behavior and Behavioral Change. The importance of behavioral factors for preventing the spread of HIV/AIDS is well known. While behavioral research directly related to HIV/AIDS has been supported, the AIDS field could benefit from fundamental research on behavior and behavior change processes (e.g., what factors influence high-risk behavior of all sorts, what is the natural history of behavioral change, what are the most opportune strategies for maintaining long-term behavioral change). NIA researchers are especially knowledgeable and could provide expertise in understanding behaviors and behavioral change over the life course.

Family dynamics and relationships. AIDS research is just beginning to examine the role of families in HIV/AIDS risk, prevention and treatment as well as the impact of the disease on family functioning. This research effort can be strengthened by attention to conceptual and methodological research on basic family dynamics, relationships and exchanges. NIA researchers can contribute basic research on family structure, functioning, and interactions to enhance scientific understanding of factors related to mobilization of social supports for preventing, treating, and managing HIV/AIDS within the family unit.

Consumers and Changing Health Care Systems. The rapid spread of AIDS has affected and will be affected by the health care system and care practices. Attention is urgently needed to understand the myriad factors which are influencing rapid changes in the organization and delivery of care, and how such changes impact on the availability and appropriateness of increasingly consumer driven health care. For example, NIA researchers are just beginning to explore the role of intra- and inter-organizational factors in meeting the health care needs of an aging society. Building on a recent workshop on Aging and Primary Care: Organizational Issues in the Delivery of Care for Older Americans, we would like to develop an initiative that specifies existent and emergent health care forms (e.g., managed care), and evaluates the effectiveness of different care models in providing care for specific health care and social needs.

Future Directions and Coordination with Other ICDs

NIA sees its contribution as: 1) ensuring that older people are included in ongoing studies/surveys of AIDS-related risk behaviors conducted by other ICDs, 2) working with other ICDs to examine topics of mutual interest (e.g., exploring intergenerational aspects of AIDS-related care); and 3) incorporating more AIDS research into ongoing NIA priorities and initiatives (e.g., identifying AIDS-related research of relevance to new women's health initiative that will bring greater attention to sexuality across the life course). In addition to these collaborative efforts, there is a need to develop NIA-sponsored program announcements in order to proactively address previously ignored research questions that are of relevance to an aging population.

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